

## IMPACT STATEMENT: *My heart aches every day. Is anyone listening?*

### Preamble

This document is intended to convey the profound impact of prolonged separation on residents of long-term care homes (LTCHs) and their spouses/partners due to visiting restrictions implemented in response to COVID-19. In essence, it has been prepared to capture the experience and reflections of nine local couples who have deeply experienced this separation first hand – their thoughts, their feelings and the harm to which they have been exposed — and in their own words.

*“I am already grieving the loss of my husband because of dementia. It is bad enough without this forced separation which is cruel punishment for two people at the end of their lives. We don’t deserve this.”*

*“I am his partner and have been with him through everything. I want to be able to go into the home to be with him to hug him to hold his hand and take him out on the patio for fresh air. I want to do the things that they don’t always have the staff to do.”*



### Situation

Sudden and drastic changes to LTCHs visiting policies in Ontario in response to COVID-19 resulted in extreme disruptions to the daily lives of residents and their spouses/partners. The prolonged period of separation has inflicted profound harm on both residents and their spouses, with many commenting on how small and sad their worlds have become. Of course, none of this was been intentional. Perhaps, however, it may have been avoidable. This must never happen again.

### Background

In March 2020, people visiting those living in LTCHs were prevented from entering the homes. This included long-time spouses of residents, many of whom visit on a daily basis.

Media stories about people with spouses/partners residing in LTCHs have been far fewer than those about being separated from a parent in LTCHs. In fact, spouses/partners feel that their stories have not been sufficiently heard. They have drawn deeply on the support of one another during these times; times often filled with a sea of emotions and characterized chiefly by feelings of hopelessness and despair.

They describe the desperation they feel daily to do whatever it takes to be with and there for the life partners. They speak with frustration about having the deep bonds of their marriages disrupted and being deprived of all that means/represents.

*“Let me at least see him and hug him while he still knows who I am.”*

*Spouses and partners of LTC residents (01 October 2020)*

Spouses/partners find peace in presence and privacy and crave opportunities to reassure their loved ones that they are not forgotten or alone, and that in a very real way, they still have a voice. They are deeply concerned about the changes they have witnessed with respect to the declining health, wellness and quality of life of their loved ones over the past six months.

They are left feeling that they have been banned, locked out, put on hold, devalued, unheard and treated in a way that has been less than humane. They have been offended and angered by the not so implicit message that has been conveyed — that they are somehow considered *nonessential* — the very idea of which negates and disqualifies the importance of their relationships and the love and care they provide every day to their spouses/partners.

*"I need physical contact with my spouse. I need to hold her hand and she needs to hold mine. I see her disappearing and I need to be at her side during this journey. I am afraid that she will forget who I am."*

*"He is my husband. He is my soul mate. He is my best friend. He trusted me with his life — and his care and happiness."*

### **Impact**

Spouses/partners do not feel as though their voices have been heard. They have tried to be patient, to keep a positive attitude, to hold it together when all they want, and are asking for is the chance to hold the hands of their loved ones.

The time they spend caring for their spouses/ partners is important to them. This time is meaningful and makes a difference to their lives and those of their loved ones

*"I would take my husband for walks a lot! To keep him from becoming stiff – and it was good for his mental and physical well being."*

*"I would go every day to help my husband fill his day and do things with him and for him to make him feel loved."*

Spouses are left asking themselves a number of questions, a few of which include:

- Does he understand what is going on? What is he thinking?
- Does he recognize me in a mask? Can he even hear me?
- Is he scared by what he is seeing?
- Will he know who I am when this is over and in what condition will he be?

Visiting options made available were less than effective and not satisfactory to those wishing to visit their spouses/partners in LTCHs.

*"Window visits didn't work. He got frustrated at seeing me and not being able to get to me. At the end of June, he started to become agitated by his reflection in the glass. He became upset and thought someone was following him. He eventually suffered the same distress during our Face Time chats."*

*"I can't really say I am visiting outside the window because it is far from a visit. The window can't be opened. My husband can't hear me. I communicate by writing notes but I am not even sure he can read anymore. I bring balloons and tape things to the outside of his window. I stick ornaments in the grass. I*

*blow bubbles for him. I make faces to try and get him to laugh and on and on. I would turn somersaults if I could. I do everything that I can to make him know that I am there and that I care. And I have been doing this every day since this all began.”*

A particularly traumatic experience occurred when the husband of one of the spouses was admitted to a LTCH early during COVID-19. Upon arrival, her husband was brought into the building and she was required to remain outside. There was no opportunity for her to accompany him to his room and help him get settled.

*“I have no idea where his room is or what is in it. He was just taken away and then put in isolation for 14 days. He was in a room by himself wondering where I was and why I wasn't coming in. In that 14 days of isolation he forgot how to walk because no one took him for a walk or kept him moving.”*

In all cases, spouses/partners were taking the same precautions as members of the staff. They wondered why they were deprived of the opportunity to hug and hold the hand of their loved one when this practice was permitted of the staff. Being deprived of the opportunity to visit in different ways has had dramatic impacts on the lives of both spouses/partners.

*“I just returned from standing outside the window of my husband's room at a LTC facility, where I have been every day since this all began. He would hardly look at me. He was so despondent, and so was I. I could not engage him no matter what I did. And this is happening most days now. These days I often leave in tears.”*

This document has been prepared in response to the experiences and reflections of nine couples who have been deeply affected by separation firsthand during COVID-19 – experiences that will have what is sure to be longstanding impacts on their families and that will not soon be forgotten. Their thoughts about current and future consideration are captured in the companion position statement entitled *I am not a visitor. I am his wife and life partner.*

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Three spouses/partners chose to remain anonymous

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